Health Technical Services Project

Discussion Papers on
HIV/AIDS Care and Support

Palliative Care for HIV/AIDS in Less Developed Countries

Prepared by
Linda Sanei

Discussion Paper Number 3

June 1998

UNITED STATES AGENCY FOR INTERNATIONAL DEVELOPMENT

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About HTS

The Health Technical Services Project provides short- and medium-term technical assistance to USAID — specifically, to regional bureaus, regional and country missions, and the Office of Health and Nutrition in the Center for Population, Health and Nutrition of the Bureau for Global Programs, Field Support, and Research (G/PHN/HN). This technical assistance supports USAID programs in maternal and child health, nutrition, health policy reform, HIV/AIDS, and environmental health. HTS activities are concentrated in three broad technical areas: project design, policy and strategy, and evaluation and monitoring.

HTS's work is grounded in the four complementary values that guide USAID's efforts to reengineer its operations:

- a customer focus
- participation and teamwork
- empowerment and accountability
- management for results.

Foreword

The U.S. Agency for International Development seeks to develop and promote effective strategies for providing basic care and support to those affected by HIV/AIDS. This series of Discussion Papers on HIV/AIDS Care and Support represents a first step in this effort.

HIV/AIDS care and support mitigate the effects of the pandemic on individuals, families, communities, and nations. Such interventions are an important component of the overall response to HIV/AIDS because they increase the impact of prevention strategies and mitigate the negative consequences of the epidemic on the prospects for sustainable development.

This series of Discussion Papers covers several key issues related to care and support:

- Human rights and HIV/AIDS
- Palliative care for HIV/AIDS in less developed countries
- Preventing opportunistic infections in people infected with HIV
- Psychosocial support for people living with HIV/AIDS
- Community-based economic support for households affected by HIV/AIDS
- Responding to the needs of children orphaned by HIV/AIDS
- Systems for delivering HIV/AIDS care and support.

Each paper provides a preliminary review of some of the current thinking and research on these broad and complex topics. It is important to note that the papers are not meant to be comprehensive — time and resource constraints prevented the authors from reviewing all the relevant literature and from contacting all the people who have valuable experience in these and related fields. Nor have they been subject to technical or peer review. Their purpose is to stimulate a broad conversation on HIV/AIDS care and support that can help USAID define its future program activities in this area. We welcome your participation in this process.

Two additional papers on the topic of voluntary counseling and testing were prepared with USAID support:

- The Cost Effectiveness of HIV Counseling and Testing
- Voluntary HIV Counseling and Testing Efficacy Study: Final Report.

These two papers are available from the IMPACT Project, Family Health International, 2101 Wilson Boulevard, Suite 700, Arlington, VA 22201; www.fhi.org.

Please direct your requests for copies of papers in the Discussion Series on HIV/AIDS Care and Support and your comments and suggestions on the issues they address to the Health Technical Services (HTS) Project, 1601 North Kent Street, Suite 1104, Arlington, VA 22209–2105; telephone (703) 516-9166; fax (703) 516-9188. Note that the papers can also be downloaded from the Internet at the HTS Project's web site (www.htsproject.com).

—Linda Sanei, Technical and Program Advisor,
Health Technical Services Project

Contents

LIST OF FIGURES

Palliative Care for HIV/AIDS in Less Developed Countries

Traditional palliative care models emphasize patients' physical, spiritual, and psychosocial comfort during the terminal stages of illness and were developed in response to the needs of cancer patients, where there is a relatively clear demarcation between active curative care and palliation. HIV/AIDS has challenged this traditional paradigm, because the divisions between active curative care and palliation are much less clear. Palliative care for HIV/AIDS thus encompasses a much broader set of interventions, from initial diagnosis to the final stages of the disease, in response to the physical, emotional, psychosocial, spiritual, and bereavement needs of people living with HIV/AIDS and their families and caregivers. This discussion paper articulates the ethical underpinnings of palliative care, describes the paradigm shift, and examines the clinical components of palliative care for HIV/AIDS, with an emphasis on nutritional support. It explores alternative therapies, discusses the challenges of delivering palliative care in less developed countries, and outlines some linkages between palliative care and prevention. It suggests that palliative care is comprehensive care which is affordable and can often be delivered in the home, when there is a well functioning referral system and supportive family structure.

The overall goals of palliative care are to relieve, improve or control symptoms, and maximize quality of life (Schopper and Walley 1992). The palliative approach emphasizes the importance of the psychosocial and spiritual as well as the physical needs of the person living with HIV/AIDS and includes consideration of the family and caregivers (Finlay and Jones 1995).

SEEKING CLARITY ON THE DEFINITION OF PALLIATIVE CARE

Much of the literature reviewed on HIV/AIDS care reveals a basic consensus on the goals or ethical underpinnings of palliative care but no clear definition of what constitutes palliative care and no clear demarcation of when palliative care begins in the disease process.

Some describe a traditional palliative care model, where medical care and psychosocial support are offered at the end or terminal states of the disease, when death is imminent. Others describe palliative care more narrowly, as merely a subset of medical care. Still others make a distinction between acute and palliative care.

Finally, there is a broader definition of palliative care, to which this paper subscribes. Under this broad definition, palliative care begins at diagnosis, is an integral part of the spectrum of care, and encompasses physical, emotional, psychosocial, spiritual, and bereavement support. According to this definition, palliative care is not limited to the terminal stages of the illness.

This discussion paper begins with a review of the ethical and philosophical basis for palliative care and the paradigm shift that has expanded the definition of palliative care to reflect a more holistic approach to treating people living with HIV/AIDS. It then focuses on some elements of the clinical components of palliative care for HIV/AIDS, with an emphasis on nutritional support and an exploration of some alternative therapies. The paper discusses how this paradigm shift can be translated to less developed countries, and why palliative care is a foundation for HIV/AIDS prevention activities. Several key aspects of palliative care are not covered in detail here, because they are examined by other discussion papers in this series. This includes prevention and treatment of opportunistic infections, a critical component of clinical palliative care (Kaplan et al. 1996/1998), and psychosocial support (Schietinger 1998).[1] Annexes to this paper include the World Health Organization's "Golden Rules" for safe food preparation; a partial list of guides, manuals, and other resources on home care for people living with HIV/AIDS; a bibliography of materials on HIV/AIDS care in general and palliative

[1]See also the papers on human rights (Lazzarini 1998), economic support (Donahue 1998), and systems for delivering HIV/AIDS care and support (Schietinger and Sanei 1998).

care in particular; and a grid that demonstrates the interrelationship between HIV/AIDS palliative care and prevention.

THE ETHICAL AND PHILOSOPHICAL BASIS OF PALLIATIVE CARE

There is a basic consensus on the rationale for palliative care and for at least some minimum standards of care, as outlined in Latimer and Dawson (1993), from which this section is drawn.

Palliative care is based on the following ethical and philosophical beliefs:

- People who are dying are of individual worth and value.
- Patients' autonomy and control are to be respected.
- The relationship between caregiving professionals and patients should be one of integrity and truth, blended with sensitivity and compassion.
- Patients who are dying must be permitted to live their remaining lives in a manner consistent with their belief systems, personalities and values. Health care providers and society must strive to be flexible.
- The intent of palliative care is to neither hasten nor inappropriately prolong the dying process.
- Bereavement support is an essential component of the palliative care continuum; it must be available to the patient, loved ones, and the community and must extend beyond the death of the patient.

Effective palliative care services have the following goals:

- a patient who is alert and comfortable and who understands the situation to the degree that he or she wishes or is able
- a family or relationship group that feels supported and assisted
- a professional staff group that understands the goals of care, accepts the ethical basis of good palliative care, and has the expertise and compassion to deliver quality care.

Effective care requires the following:

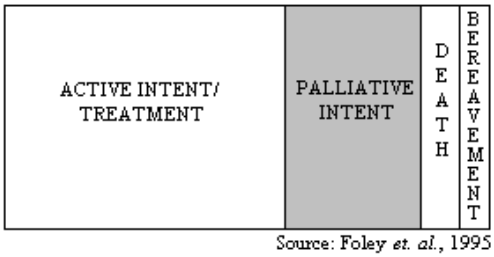
- an accurate assessment of the patient's and family's needs for physical and emotional care and appropriate planning to ensure that these needs are met
- the commitment of a team of care providers
- easy and early access to palliative care services as the needs of the patient and family dictate
- a variety of settings for care with sufficient and effective resources in each
- effective follow up and continuity of care.

A Paradigm Shift in Palliative Care: Taking a Holistic Approach

Traditional palliative care models were developed in response to the needs of people living with cancer, a disease for which there is a relatively clear definition between active curative care and palliation, as shown in Figure 1 (Foley et al. 1995; Grothe 1995). "With cancer the transition between curative care and palliative care is relatively easily marked, facilitating the decision of when to offer hospice care to the patient and family" (Grothe 1995). In HIV/AIDS, on the other hand, the divisions between curative and supportive/palliative care are highly variable and less well defined, as shown in Figure 2 (Foley et al. 1995).

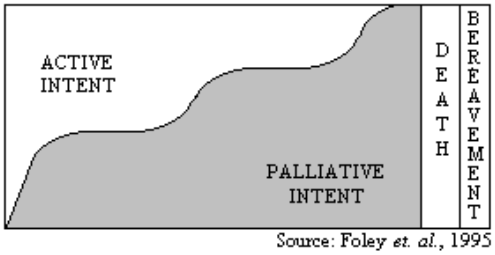
> AIDS…has a course like a roller coaster ride, from the low of one serious opportunistic infection to the high of treatment and response, and then another dip due to the next infection. It is not until wasting becomes apparent that the course of AIDS achieves the predictability of cancer… Thus AIDS is a disease that is ultimately fatal but whose manifestations are frequently treatable. (Grothe 1995)

It is this variability or up-and-down nature of HIV/AIDS (sometimes referred to as the "Lazarus Syndrome") that has challenged the health system, the providers of care, and the patients themselves and has shifted the palliative care paradigm to one that is more all-encompassing (Foley et al. 1995). Palliative care for HIV/AIDS thus includes a much broader set of interventions, from initial diagnosis to the final stages of the disease and does not concentrate only on comfort measures during terminal stages of illness.



Source: Foley *et. al.*, 1995

Figure 1: Cancer Care



Source: Foley *et. al.*, 1995

Figure 2: AIDS Palliative Care

In summary, traditional palliative care models are inadequate to meet the needs of people living with HIV/AIDS (PLWHAs). In addition to suffering multiple and variable medical problems during the progression of their disease, they also experience discrimination, rejection, and alienation because of the stigma attached to the disease itself (Foley et al. 1995). Meeting these complex medical, psychosocial, spiritual, and emotional needs through palliative care is a challenge, particularly in less developed countries, where limited health budgets are already stretched thin by the growing burden of HIV/AIDS prevention, care, and support.

> …we are confronted with a biological and social challenge that does not fit traditional models of patient care management. The disease and its impact are not static: changes in the demographics of the HIV–infected population, changes in treatment, and changes in other social factors contribute to the need for a dynamic response… (Goldstone 1992)

CLINICAL COMPONENTS OF HIV/AIDS PALLIATIVE CARE

Under the broadest definition, the clinical components of palliative care include management of the common ailments or symptoms associated with the progression of HIV disease, including pain control; nutritional interventions to prevent loss of lean body mass (LBM); and prevention and early diagnosis and treatment of opportunistic infections (OIs).[2]

Many people living with HIV and AIDS in industrialized countries also seek alternative treatment therapies, usually as a complement to conventional medical therapy and as part of a broader search for a cure, symptom relief, pain alleviation, stress reduction, and hope. In most developing countries, many PLWHAs turn to such alternative therapies first, and use conventional medical therapies later, often as a last resort.

An issue related to clinical palliative care for HIV/AIDS that is worth noting is the role of health professionals.[3] People living with HIV/AIDS must take responsibility for determining how they will live and manage their disease. Health professionals must recognize the need of PLWHAs to determine the course of their care, while understanding that their feelings of fear, anger, sorrow, guilt, and shame can affect their decision-making.

Health professionals are in a position to provide care that respects this need for self-determination and the dignity of the individual while also setting an example of appropriate, non-judgmental behavior for other health workers, community members, and family members. Health professionals should seek to develop a supportive relationship with patients and to guide patients' decisions by providing them with information upon which to make sound decisions. The International Council of Nurses (ICN) and World Health Organization (WHO) issued a Joint Declaration on this subject, which quotes the ICN's Code for nurses:

> The nurses's responsibility is to those people who require nursing care…in providing that care she/he promotes an

[2]As noted, prevention and treatment of opportunistic infections, a critical component of clinical palliative care, is covered in Kaplan et al. (1996/1998).

[3]This passage is drawn from Guidelines for Nursing Management of People Infected with Human Imminodeficiency Virus (HIV) (WHO 1988).

> environment in which the values, customs and spiritual beliefs of the individual are respected. (WHO 1988)

Treating the Common Ailments of HIV/AIDS

Many of the afflictions commonly suffered by people with HIV/AIDS can be treated in the home, and a number of home care manuals have been developed for Western and non-Western audiences. Many of these are listed in Annex A.[4] These manuals and guidebooks generally review what can be done in the home to treat these common ailments and when outside help is appropriate.

The common ailments that can usually be treated at home successfully include: lack of appetite, malnutrition, fever, cough, difficulty breathing, nausea, vomiting, diarrhea, pain, tiredness and weakness, mental confusion and dementia, and depression and anxiety. A number of common skin ailments can also be treated at home, including rashes, itching, painful sores, dryness of the skin, slow healing of wounds, boils and abscesses, yeast infections (thrush, candidiasis), fungal infections (ringworm), bacterial infections, shingles, bed sores, eczema, Kaposi's sarcoma, and skin conditions that result from poor hygiene or from allergies to medicines or skin irritants (WHO 1993a).

Keeping patients clean and dry, comfortable, and well fed and hydrated are extremely important, but a variety of medicines and approaches can also be used to treat these common ailments:

- nutritional approaches for nutrition-related problems
- antibiotics for certain infections and diseases caused by bacteria
- medicines for fever and pain: aspirin, paracetamol, codeine, and morphine
- medicines for diarrhea: oral rehydration salts (ORS), adsorbents, and antimotility medicines

[4]The listing in Annex A is not meant to be comprehensive; it represents those materials that could be obtained and reviewed during preparation of this paper. There likely exists a number of additional care manuals that are tailored for use in particular localities. The enormous contribution of WHO/GPA in the field of care cannot go unrecognized. Many of the excellent manuals and treatment guidelines listed in Annex A were produced by WHO/GPA, in particular, WHO's *AIDS Home Care Handbook* (WHO 1993a).

- medicines for skin problems: calamine, genetian violet, potassium permanganate, hydrogen peroxide, nystatin, clotrimazole, ketoconazole
- medicines for nausea and vomiting: anti-emetics. (WHO 1993a)

Pain Management

Controlling pain is an important aspect of palliative treatment, assuming medications are available and accessible, because pain management contributes significantly to improved quality of life (Tobin et al. 1993). In the mid–1980s, the WHO launched a simple, inexpensive method for controlling pain — "the three-step analgesic ladder" outlined in Figure 3 — and 48 countries have developed policies to adopt this approach (WHO 1994).

Figure 3. The WHO Three-Step Analgesic Ladder

For Mild Pain Acetaminophen Non-steroidal anti-inflammatory agents (NSAIDs) such as ibuprofen
For Moderate Pain Continue to receive acetaminophen and NSAIDs, if appropriate, with addition of weaker opioid agent such as codeine
For Severe Pain Acetaminophen with the addition of morphine

Source: Tobin et al. 1993.

Morphine is an important drug in HIV/AIDS pain control during the final stages of the disease. However, controls on its distribution limit its legal availability to most poor countries (World Bank 1997). A 1994 WHO report described at least 50 countries where morphine was not available, 27 of them in Africa and 9 in the Americas (WHO 1994).

Nutritional Support

Nutrition is a cornerstone of good health (Greif and Golden 1994). Nutritional status influences morbidity and mortality for many diseases, regardless of the disease process. Hence, nutrition interventions are fundamental in the early stages of HIV/AIDS and in the ongoing treatment of HIV/AIDS (Elbein 1995).

The importance of nutrition in HIV/AIDS was recognized early in the epidemic, as a result of the unexplained chronic wasting associated with the disease in Uganda, where it was known locally as "Slim Disease" (Keusch and Thea 1993). Wasting is characterized by a significant loss of lean body mass (LBM), which is associated with an increased incidence of opportunistic infections, further deterioration of immune function, and a deterioration of nutritional status. This is a process that spirals downward to result in profound malnutrition and, ultimately, death (Elbein 1995; Keusch and Thea 1993; NIAID 1998).

In fact, the typical manifestations of AIDS in Africa were pulmonary tuberculosis, chronic diarrhea, and weight loss in heterosexual adult men and women. In contrast, in the United States and Europe, the disease was initially marked by Kaposi's sarcoma or pneumonia due to Pneumocystis carinii in previously healthy young homosexual males (Keusch and Thea 1993). This led WHO to add chronic diarrhea and weight loss to its case definition of AIDS in Africa and, shortly thereafter, led the U.S. Centers for Disease Control (CDC) to modify its case definition of AIDS in the United States as well (Keusch and Thea 1993). Hence, wasting and diarrhea are common in the course of AIDS, despite geographic or genetic origins.

Many factors appear to contribute to wasting (also referred to as protein-calorie malnutrition or cachexia). These include inadequate dietary intake, malabsorption of nutrients, abnormalities in metabolism and energy expenditure, and HIV–related opportunistic infections. Reduced calorie intake often results from patients' loss of appetite (due to nausea), diarrhea, and oral, pharyngeal, and esophageal sores. Dr. Stephen Marriage noted at the Second International Conference on Nutrition and HIV Infection in August 1997 that the clinical picture is further complicated in HIV–infected children by the metabolic demands underlying growth (as quoted in MacDougall 1997).

Early intervention and counseling are critical. Ideally, nutritional considerations should begin when a patient is first diagnosed as HIV–positive (Casey 1997), and weight maintenance should be a critical part of dietary management goals. Unfortunately, according to Dr. Norma Muurahainen, Medical Director of the

Ryan White Program at Graduate Hospital in Philadelphia, "Nutrition has been too often neglected in mainstream medicine, and too many HIV–infected patients are receiving too little nutrition too late" (as quoted in MacDougall 1997). One challenge, according to Dr. Muurahainen, is to identify markers of adequate nutritional status:

> Serum albumin and micronutrients have been studied as potential surrogate markers of nutritional status, but these indices can be altered by opportunistic infections and other acute and chronic illnesses. Body weight by itself is an inadequate marker of nutritional status and the correlations between nutritional status and body composition variables are poorly understood. (as quoted in MacDougall 1997)

An enormous amount of promising research has been undertaken or is underway in the field of nutrition and HIV, but nothing has emerged as a "magic bullet" to halt the inevitable wasting that accompanies the disease.

> It is not surprising, therefore, that dietary therapy for AIDS has been proposed, debated, and more importantly surreptitiously or overtly used from the early days of the epidemic. These therapies have not only reflected current practices in modern nutrition…but also unproven concepts arising from continuing faddist and unscientific influences on the field. It has not always been easy for the public…or even the medical community itself, to dissect out the truths from the theories and the manifest from the myths. (Keusch and Thea 1993)

Many approaches are being used to maintain nutritional status and to slow or reverse weight loss, some of which are reviewed below.[5]

[5]Use of appetite stimulants, anabolic agents, cytokine inhibitors, and hormones are undergoing clinical trials in the United States and are not reviewed here.

Dietary Interventions

Food and diet play an essential role in maintaining health, strength, and quality of life (Greif and Golden 1994; HAIN 1998a). In many communities that have been hit hard by HIV/AIDS, food security is a primary concern; indeed, in much of the literature on HIV/AIDS care in less developed countries, food is mentioned as a primary need above all other basic needs.

Many factors affect nutritional adequacy in resource-poor settings, including complex social, political, geographic issues, among others. In a speech to the Second International Conference on Nutrition and HIV Infection, Dr. Rudolph Wabitsch of UNAIDS noted that "The problems of providing food aid to developing countries are myriad and center heavily on distribution factors" (as quoted in MacDougall 1997). Therefore, even where food supplies are adequate, food may continue to be unavailable to the most vulnerable populations. For instance, the World Food Program orchestrated a $5 million donation of food aid to HIV–infected people in Uganda, but it was later discovered that Uganda's supplies of food were adequate but that mechanisms for food storage, transportation, and distribution were virtually nonexistent (Wabitsch, as quoted in MacDougall 1997; see also Donahue 1998).

Diet is one avenue through which people living with HIV/AIDS can play an active role in managing their disease, as can their families and communities. Few if any of the vast array of special diets and foods that have been suggested to boost immune function and prevent infections — strict vegetarian, macrobiotic, anti-candida, single-food diets, etc. — are recommended. These diets, many of which require careful planning and preparation, often lack critical nutrients, energy density, and calories ,and should be discouraged on the grounds that they promote weight loss, leading to faster progression to death (Summerbell 1994). For example, many include only whole grain cereals, fresh fruit, and vegetables, with little or no meat or sugar.

Individuals are advised to choose a complete diet from available local foods with respect to protein quantity and quality, energy intake, and fiber. Diets should include adequate amounts of simple and complex carbohydrates, fats, and proteins. Attention also needs to be given to ensuring adequate hydration and consumption of foods rich in vitamins and minerals. The best sources of vitamins and minerals include all fruits and vegetables, animal products, and fortified food products.

Protein plays a pivotal role in maintaining lean body mass. The best-quality proteins are from animal sources, such as beef, pork, poultry, fish, shellfish, eggs,

milk, and milk products. Other sources of protein include peas, lentils or beans, soya, groundnuts, seeds, and nuts (WHO 1993b).

Energy intake is also critical. Some foods can be made more energy-dense and easier to digest. For instance, "porridge can be made more energy-rich by adding nuts or oil, by replacing some of the water with fresh milk or coconut milk, or by adding mashed fish, dark green or orange fruits and vegetables or fruit juice" (HAIN 1998a). Other energy-dense foods include potatoes, yams, cassava, taro, plaintains, sugar, wheat, rice, millet, maize, animal fats and vegetable oils (WHO 1993b).

Food safety is a critical consideration, because "people with HIV are 20 times more likely to contract food-related illnesses than individuals without HIV" (Elbein 1995). Special precautions are often needed when cleaning, preparing, and storing their foods. The World Health Organization has developed Rules for Safe Food Preparation, which are outlined in Annex B, and guidelines for appropriate nutrition are covered in many of the care manuals reviewed in Annex A.

Many people have sought alternative treatments to complement other dietary interventions, including herbal teas[6] and vitamin and mineral regimens. To date, no definitive statement can be made regarding the efficacy of herbal teas, but they do have the potential to cause uncontrolled, even toxic, pharmacologic effects, given that they are basically drugs in nonpurified forms (Elbein 1995; Summerbell 1994). They can also be expensive, quickly consuming limited household financial resources. Complex vitamin and mineral regimens, which emphasize large doses of certain vitamins and minerals (megadosing), are also cautioned against (Summerbell 1994).

Vitamins and Minerals

The work of Friss and Michaelson (1998), which builds on Tang at al. (1993, 1996, 1997a, 1997b), describes an important relationship between micronutrient status and the progression of HIV. There is a growing body of suggestive evidence that point to vitamins A, B complex, C, E, niacin, and selenium as being most promising. The role of other micronutrients, such as iron and zinc, and the role of Vitamin A and other antioxidants, appears more complex; in fact, high intake of

[6]Herbal medicines are discussed in more detail under the section on Alternative Therapies.

these may be harmful (Friss and Michaelsen 1998; Tang et al. 1997; Summerbell 1994).[7]

The results of these and other important studies will help international organizations and individual countries formulate specific nutrition guidelines and policies concerning vitamin and mineral supplementation. Until such time, multi-vitamin and -mineral supplements are only recommended if an individual is unable to obtain an adequate balance of nutrients through diet (Summerbell 1994). Friss and Michaelsen (1998) point out that an optimal diet is generally unavailable in developing countries and that it may be operationally feasible and affordable to give targeted micronutrient supplements to high-risk populations via the primary health care system. Research is needed to provide firm evidence that there is a clear survival benefit to such supplementation and to determine the appropriate supplement formulation for HIV–infected individuals (current recommended dietary allowances, or RDAs, are established for healthy populations).

Lipids and Amino Acids

There is some increasing evidence that immune function can be manipulated by altering the lipid or amino acid composition of the diet (Summerbell 1994). Some of this research suggests an effect by medium-chain saturated fatty acids — such as those found in lauric oils (coconut oil or palm kernel oil) — on viral replication (Enig 1998). Should research prove that lauric oils have antiretroviral properties, it is important to note that these substances are already included in the diets of many people around the world. In summary, however, although altering dietary lipids and amino acids may have a place in managing HIV disease, the existing data are not strong enough to make recommendations on such changes at this point (Summerbell 1994).

Exercise

Recent research suggests that exercise may have a significant impact on several important components of good health with no negative effects on CD4+ cell counts (the key immune parameter in HIV/AIDS):

> Some of the physical benefits noted are: an increase in cardiopulmonary fitness, improved muscle function, and

[7] Friss and Michaelsen (1998) recommend further research in this area and suggest the use of multi-micronutrient supplementation as a study intervention, if possible using a factorial design.

> weight gain, while psychological benefits consisting of improved mood states and increased active coping behaviors, have been observed. (LaPerriere et al. 1997)

So promising is this research that the Pan American Health Organization (PAHO) is currently incorporating a module on exercise in their publication for the region, *Guidelines for the Domiciliary Care of People Living with HIV/AIDS.*

Summary of the Role of Nutritional Support

Some of the practical recommendations concerning proper nutrition for people living with HIV/AIDS that emerge from the research are summarized in Figure 4. There are also several key lessons for policymakers and health programmers:

- Dietary nutrition interventions are fundamental to HIV/AIDS care.
- Early nutritional interventions and counseling are critical.
- Nutritional status must be monitored.
- Aggressive dietary management during and after opportunistic infections is critical.
- Protecting the food supply and ensuring that foods are targeted to the most vulnerable are priorities.
- The research is inconclusive on the survival benefits to PLWHAs of micronutrient supplements, and alterations in lipid or amino acid composition of the diet, and it is therefore premature to make recommendations in these areas.

Figure 4. Practical Recommendations for the Nutritional Management of People Living with HIV/AIDS

- Provide nutritional education at the point of initial contact with the patient. This includes conducting a nutritional assessment, creating a nutritional plan, and providing nutritional guidelines.
- Monitor nutritional status
- Diagnose and treat problems as they arise. Control of infection is important because it permits some degree of nutritional rehabilitation
- Initiate dietary interventions early
- Provide extra nutritional support during the convalescent period following infections
- Avoid unproven pharmacologic manipulations of specific nutrients, including mega-dosing of micronutrients
- Choose complete diets with respect to quantity and quality, energy intake and fiber
- Take frequent small meals to ensure adequate intake and avoid nausea
- Use oral feeding whenever possible and enteral feeding when oral intake is not possible
- Avoid parenteral alimentation
- Emphasize food safety and food hygiene (see Annex B)

Source: Guidelines for Nutrition Support in AIDS, published by the Taskforce on Nutrition Support in AIDS (Keusch and Thea 1993)

ALTERNATIVE THERAPIES

> Worldwide, the World Health Organization reports that 80 percent of people use some type of treatment or modality that is popularly considered complementary/alternative medicine in the U.S. (Hanna 1998a)

People in the West are increasingly seeking alternative treatment therapies as a complement to conventional medical treatment.[8] The tradition of seeking alternative treatments is long-standing in many less developed countries, where most people commonly seek alternative treatments first and conventional medical therapy later, often as a last resort.

The alternative treatments sought for HIV/AIDS range from self-care according to folk principles, to care delivered in an organized health care setting based on such traditions and practices as acupuncture, homeopathy, and Tibetan and Traditional Chinese medicine, to name a few (Hanna 1998a).

Research on the efficacy of different alternative treatment therapies is ongoing, but most studies conducted to date have not been subjected to rigorous Western scientific inquiry, and much of the information about the value of alternative treatment modalities for HIV/AIDS is therefore anecdotal. This anecdotal information indicates that alternative therapies offer positive psychological benefits, which are often attributable to the treatment process itself, rather than the therapeutic value of a specific agent or therapy:

> The simple act on the part of the patient of seeking medical assistance and making decisions about how to better one's health may have extremely powerful health benefits. Although the benefits thus may be seen as psychologically based, they are nonetheless real. (Hanna 1998b)

Despite these positive benefits, there remains little scientifically conclusive evidence about the efficacy of many types of alternative therapies. And some literature cautions PLWHAs and their families, especially in resource-poor

[8] According to articles in recent issues of the *Archives of Family Medicine* and the *Annals of Internal Medicine,* approximately half of all adults in the United States use some type of alternative/complementary therapy (Hanna 1998a).

settings, not to expend limited resources on alternative therapies, which are often expensive, and encourages them instead to use limited resources to purchase food and other essentials.

Some types of alternative therapies, such as massage, meditation, or yoga, involve little or no risk and have been noted to have an enormous positive effect by reducing stress, alleviating depression, and enhancing overall quality of life (Hanna 1998a).

Other therapies, while offering the potential to help, can also cause harm and must be regarded and approached differently (Hanna 1998a).[9] Herbal medicines fall into this category, and because of this and the widespread attention such treatments now receive, these are covered in some detail here.

Herbal Medicines

As noted, herbal teas and other preparations are actually drugs in nonpurified form, which may produce both beneficial and detrimental outcomes (Elbein 1995). For example, the CDC reported deaths associated with the use of the herb ephedrine (ma huang) in teas and other herbal formulations (Hanna 1998a). At the XI International Conference on AIDS in July 1996, Dr. Sherwood Gorbach reported near-fatal reactions to other herbal preparations used by PLWHAs: chaparral, germande, comfrey, mistletoe, skullcap, margosa oil, Gordolobo yerba tea, Kombucha tea, pennyroyal (squawmint oil), and some types of Mate teas (Hanna 1998b).

There is also the potential for powerful drug/herb interactions, which can cause toxic or even life-threatening reactions in the body's metabolic and excretory systems and can create a distorted clinical picture, making diagnosis more difficult. Other herbs have been linked to certain birth defects, and their use may also be contraindicated in pregnant women. (Hanna 1998a) The use of vaginal herbs/substances has been the subject of two studies in Africa, where it is believed that the practice of using herbs as part of a "dry sex" custom may actually

[9]The literature reviewed for this discussion paper most frequently discussed the use of acupuncture and herbal medicines, although a myriad of other treatments, approaches, and philosophies were also mentioned, including bio-electromagnetic applications, biofeedback, colonic irrigation, crystals, homeopathy, hypnosis, massage, relaxation exercises, paced breathing, visualization/guided imagery, therapeutic touch, and *reiki* (Greif and Golden 1994; Hanna 1998a).

contribute to increased risk of HIV transmission (Hanna 1998b; Runganga and Kasule 1995; Civic and Wilson 1996).

Still, the proponents of herbalism point to data on the benefits of such treatments:

> …despite a lack of modern controlled clinical trials, the possible efficacies and toxicities of many herbal remedies have been well studied over the course of hundreds or thousands of years. (Hanna 1998a)

> …documented medicinal use of plants and herbs to treat illness or to promote health dates back at least to the time of the ancient Egyptians. Documentation dated around 1500 BC describes 700 plant-derived medicines. Other documentation exists from Greece and from Western Europe, from 400 BC through the Medieval period and into the present. The history of herbalism in Europe and China is similarly lengthy and continuous. (Hanna 1998b)

Many herbs have been used in HIV disease management, although no definitive statement can be made regarding their effectiveness. They include:

- tea tree oil for fungal infections
- a garlic extract (allicin) for cryptosporidiosis
- sage for night sweats
- slippery elm for diarrhea
- echinacea for HIV infection.

Research on Alternative Treatments

As noted, much of the data on the efficacy of alternative treatment therapies are anecdotal, and few studies have been subjected to rigorous Western scientific inquiry. However, a number of research projects are now underway in this area.

Some herbs that have aroused interest in researchers for potential application, include curcumin, glycerrhizin (licorice), hyssop (Hyssopus officinalis, being developed in Japan), and lentinan (shitake mushroom). In addition, “Certain plant polysaccharides (sugar chains) are being evaluated for immune stimulation in the

U.S., Switzerland, and Japan" (Hanna 1998b). St. Johns Wort (Hypericum perforatus) has been clinically tested and approved in Germany for the treatment of mild-to-moderate depression. However, "study design and precepts…may differ appreciably from procedures in the U.S.," and consequently these study results need careful scrutiny (Hanna 1998a). In Zimbabwe, traditional medicinal remedies are being incorporated into clinical trials sponsored by the Ministry of Health (Leonard 1994).

In the United States, the National Institutes of Health (NIH) have funded over 40 research projects on alternative treatments over the past several years, and the results are anticipated in the near future. Bastyr University in Bothell, Washington, has just closed enrollment in a monumental nationwide survey of over 170 alternative therapies in the context of HIV/AIDS and received an additional $840,000 for further study (Hanna 1998a).

The results of these and other studies will help provide guidance for future policy in this area.

Below are descriptions of two studies that more carefully examine the value and efficacy of herbs as an alternative treatment therapy specifically for HIV/AIDS. Both of these conclude that further research is necessary.

Kallawaya Indian Herbal Cures (Bolivia)

The Kallawaya Indians in Bolivia use some 900 of the over 2,000 medicinal plants that grow in Bolivia, following traditions dating from 400 AD. The Society for Bolivian Traditional Medicine (SOBOMETRA), a syndicate of herbalists, preserves and disseminates Kallawaya knowledge of herbal cures. In this study, more than 10 samples of 60 species of Kallawaya medicinal herbs, representing 30 plant families, were assayed to compare their toxicity and ability to protect MT-2 T-lymphoblastoid cells from the cytopathic effect of HIV. The results are reported as a therapeutic index (TI) which was > 25 for 18 species, > 50 for seven, and > 100 for one. The anti–HIV activity resided primarily in the aqueous extracts and was concentrated in plants used in ethnomedicine to treat lung and liver diseases. These results indicate that Kallawaya medicinal plants are a potentially useful resource for developing leads to new anti–HIV drugs and suggest several lines of further inquiry and confirms the value of ethnomedicine for developing leads for new drugs. (Abdel-Malek et al. 1995)

Chinese Herbal Treatment for HIV

The only pilot, randomized controlled trial of Chinese herbal treatment for HIV–associated symptoms reviewed was conducted by Burack et al. (1996), at the Department of Medicine of the University of San Francisco. Thirty adults with symptomatic HIV infection, no previous AIDS–defining diagnosis, and CD4+ counts of 0.200-0.499 x 10^9/L (200-499/mm^3) received 28 tablets each day of either a standardized oral preparation of 31 Chinese herbs or a cellulose placebo. Primary outcome measures were changes in life satisfaction, perceived health, and number and severity of symptoms. Other outcomes included adherence, and changes in weight, CD4+ count, depression, anxiety, physical and social function, and mental health. There were trends toward greater improvements among herb-treated subjects on all symptom subscales except dermatologic. There were improvements in life satisfaction and symptoms among subjects receiving the herbal therapy. The conclusion of this study was that larger trials of longer duration would be necessary to determine whether Chinese herbs are effective in the management of symptomatic HIV infection. (Burack et al. 1996)

Traditional Healers

Perhaps the most constructive use of alternative medicine in HIV/AIDS prevention and care has been to engage traditional healers in the fight against HIV/AIDS. For example, traditional healers in Zimbabwe, in South Africa, in Uganda, and in Mozambique are collaborating with governmental and nongovernmental organizations involved in HIV/AIDS education and prevention. They have been trained in the skills necessary to prevent HIV/AIDS and to train their peers and community members. In many cases these healers are able to penetrate the culture and educate the population about AIDS where such educational efforts are considered taboo. (Mahlalela 1996; Leonard 1994; Kyeyune et al. 1996; Fleming 1995).

The partnership between the Ministry of Health in Zimbabwe and ZINATHA (Zimbabwe National Traditional Healers Association) may be the most comprehensive (Schietinger and Sanei 1998). This program mobilizes traditional healers for community-based HIV/AIDS prevention and care, and it encourages chiefs and other opinion leaders in the community to modify traditional practices that actually encourage the spread of HIV/AIDS.

CHALLENGES AND COSTS OF PALLIATIVE CARE FOR HIV/AIDS IN LESS DEVELOPED COUNTRIES

The rich traditions of palliative and hospice care and the body of literature that describes it is largely Western, although the elements of palliative care are firmly embedded in the traditions of most non-Western cultures. As evidenced by a large body of anecdotal evidence from the field, particularly in Africa, patients with HIV/AIDS already benefit from palliative care and other types of support from their immediate families, extended families, religious leaders, and community members.

Only one study of the many reviewed for this paper, which was conducted in south west Uganda, questioned the existence of a safety net provided by the extended family (Seeley et al. 1993). In this study, data were collected by counselors over a six-month period about the care given to 30 AIDS patients by their families. The study revealed 27 of the 30 received only limited care, due to lack of food, money for medications, and caregivers' other family responsibilities. For 7 of the 17 who died during the study period, other relatives were asked to help with care but refused on the grounds of poverty or other commitments. However, in all but one case, families did provide assistance with funerals.

The trend is clearly toward community-based and home care for HIV/AIDS patients in a number of countries, a response to shrinking health budgets and hospital overcrowding: "Worldwide, home care is perceived to be the solution for providing care in the face of shrinking resources for health care" (Goldstone 1995). This makes further investigation into the extended family's role in providing adequate support for HIV/AIDS patients imperative.

While home- and community-based care for palliative care for HIV/AIDS is appropriate, it is not a panacea — it merely shifts the resource burden from the health system to the community, including NGOs and, ultimately, women, who provide most home care and are also resource-poor. The expansion of community-based and home care cannot become an excuse for health systems to ignore the important role they can and must play in providing palliative care for HIV/AIDS:

> …home-based care cannot replace in-patient and out-patient services and must be part of a reasonably well functioning health care system. …Home-based care also requires a supportive family environment and as more family members become ill with AIDS, provision of care at home may no longer be possible. (Schopper and Walley 1992)

Shifting the resource burden for care to the community reinforces the important role of economic support for households affected by HIV/AIDS (Donahue 1998). Such support includes microcredit services to enhance the income-generating capacities of families and communities and support for the creation of community safety nets to assist families and households that become destitute. Such economic support is clearly encompassed within the broad definition of care used here.

The costs of providing palliative care for HIV/AIDS must be examined in light of the ongoing international dialogue about the development of effective treatment regimens and the extension of antiretroviral therapies to less developed countries. Management of OIs and antiretroviral therapy dominate the AIDS literature in industrialized countries, but the administration of life-prolonging drugs and complex drug treatment regimens assumes a comprehensive medical care system, a referral system, abundant resources, a consistent flow of medications, and access to the above, few of which exist in most developing countries. Antiretrovirals have heightened the discussion about equity, particularly because they are virtually unavailable to resource-poor countries except on an extremely limited trial basis or through a growing black market. A study now being conducted by the Joint United Nations Programme on HIV/AIDS (UNAIDS)[10] is examining the effects of introducing antiretrovirals in four countries in the Americas, and these questions about equity will likely continue to provoke vigorous debate at international HIV/AIDS conferences and meetings even as the research continues.

Even so, when asked at the 8th International AIDS Conference in Chiang Mai what they most wanted, PLWHAs indicated that their top priority was not access to antiretrovirals, but access to basic treatment and care — good, affordable nutritional advice and food supplements, information about stress reduction, treatment for pain relief, advice about herbal remedies, and the like (UK NGOs 1997). What they described were the key elements of palliative care.

This expressed need for basic treatment and care is echoed over and over again in the literature. Meeting the basic needs of PLWHAs is mentioned in reports ranging from a needs assessment/design for a community- and home-based care program in Malawi (Simon et al. 1991) to an evaluation of a community home-care program in Rwanda (Schietinger 1992), to the numerous programs described in

[10]UNAIDS was established on January 1 1996, and coordinates the HIV/AIDS activities of five UN organizations (including WHO), and the World Bank.

ACTIONAID's Strategies of Hope series.[11] The immediate basic needs most often mentioned include food, clothing, and simple medicines. PLWHAs also worry about the future of their children; they want reassurance that their children will be fed, housed, and schooled after they are gone. "People are not asking for Western-style home nursing services. They are searching for physical relief and emotional support." (Simon 1991) Caregivers express needs too — most often, for transportation, such as bicycles, to allow them to make home visits to more rural households.

This raises a fundamental question: If even the basic treatment and care needs of the majority of PLWHAs are not being met by existing health services in less developed countries, can one reasonably expect critically scarce resources to be siphoned off to purchase antiretrovirals, the efficacy of which varies from patient to patient? This fundamental issue was addressed in a recent World Bank Policy Research Report (World Bank 1997), which attempts to sort out the costs for a package of effective, affordable palliative care and treatment for people with HIV/AIDS in low-income countries (see Figure 5). The report compares the costs of this package of palliative care to antiretroviral therapy. The study concludes that the most cost-effective strategy is to provide basic palliative care for common ailments such as diarrhea, skin rash, cough, fever, headache, pain, nausea, and shortness of breath. These treatments, which are found to substantially enhance quality of life, cost an average per patient-year of $18.96 in Sub-Saharan Africa and Thailand (World Bank 1997).

All but the very poorest of HIV–infected patients are willing and able to purchase basic palliative care drugs (aspirin, paracetamol, morphine, antibiotics), yet these medications are either unavailable or in short supply (World Bank 1997). Indeed, one of the largest problems the Guatemalan Association for Prevention and Control of AIDS faces in delivering care services through its clinic programs is its lack of medications. It has only a very small fund for purchasing drugs; the remainder are provided through donations. [12]

[11]Buwalda (1994); Hampton (1994a); Hampton (1994b); Mouli (1992); Shreedhar (1994); Sittrai and Williams (1994); Williams (1994); Williams et al. (1994a); Williams et al. (1994b); Williams and Tamale (1994); and Williams and Ray (1994).

[12]Interview with Helen Cornman, National Council on International Health (NCIH), April 1998.

Figure 5. Annual Cost per Patient of Palliative Care and Treatment of Opportunistic Illnesses, Sub-Saharan Africa and Thailand (1996 dollars)

	Diagnosed episodes per 100 patient-years		Cost per episode[a]		Average cost per patient-year	
Symptom or illness	Sub-Saharan Africa	Thailand[b]	Sub-Saharan Africa	Thailand	Sub-Saharan Africa	Thailand
Palliative Care[c,e]						
Diarrhea	63		13.00		8.19	
Scaling skin rash	15		1.50		0.23	
Itching skin rash	52		2.00		1.04	
Cough	120		1.40		1.68	
Fever	105		0.60		0.63	
Headache	52		0.25		0.13	
Pain, mild	52		1.12		0.58	
Pain, severe	17		14.00		2.38	
Nausea	75		1.75		1.31	
Shortness of breath	43		6.50		2.81	
Subtotal	*594*	*594*			*18.96*	*18.96*
Treatment of inexpensive OIs						
Tuberculosis[d]	47.5	40	37.00	261.88	17.58	104.75
P. carinii pneumonia	3	20	8.00	207.76	0.24	41.55
Toxoplasmosis	0	2	8.00	207.76	--	4.16
Oral Thrush	77	77	2.00	2.48	1.54	1.91
Esophageal thrush	14	14	10.00	4.96	1.40	0.69
Pneumonia/septicemia	20	20	60.00	25.38	12.00	5.08
Subtotal	*161.5*	*173*			*32.76*	*158.14*
Treatment of expensive OIs						
Cryptococcosis	5	25	870.70	1,741.40	43.54	435.35
Herpes simplex virus	5	18	140.00	46.80	7.00	8.42
Penicilliosis	0	9	1,852.50	697.40	--	62.77
Other OIs including: Cytomegalo virus Mycobacterium avium/complex	19.5	19	717.88	717.88	139.99	136.40
Subtotal	*29.5*	*71*			*190.52*	*642.94*
Inpatient days[f]	3,000	3,000	7.25	22.44	217.50	673.34
Outpatient days[f]	12,000	1,200	2.50	13.60	30.00	163.20
Grand totals per case						
Palliative plus inexpensive OIs					*299.22*	*1,013.65*
Palliative plus all OIs					*489.74*	*1,656.59*

a. Costs per episode are estimated in Perriëns *(background paper*, 1996).

b. Frequency of various symptoms and OIs for Thailand are from Perriëns *(background paper*, 1996), or Kaplan and others (1996) or, where both give a value, an average of the two.

c. The frequency and treatment costs of symptoms listed under palliative care are assumed to be the same in Sub-Saharan Africa and Thailand.

d. In Zambia, experience suggests that preventing tuberculosis in a group of HIV-infected patients costs approximately the same as treating those in the group who get the disease (Foster, Godrey-Faussett, and Porter 1997).

e. Since palliative care involves generic drugs, these costs should be similar in all countries able to buy essential drugs in bulk through international tenders.

f. Patients in Thailand pay about 30 percent of these costs for drugs, inpatient days, and outpatient visits. The cost per patient-day in Sub Saharan Africa is taken from Chela and others (1994) .

In particular, the World Bank cites international controls on morphine distribution, an important analgesic in WHO's three-step ladder as an impediment to making this essential drug available to less developed countries. "Governments can address these problems by facilitating the availability of generic drugs needed for palliative care and common opportunistic illnesses… and adding these medications to their list of 'essential drugs'" (World Bank 1997).

Figure 5 also outlines the additional costs for treating tuberculosis (TB) and other opportunistic infections, both inexpensive and expensive. While still low in comparison with antiretroviral therapy, even these costs exceed by several times the total annual per capita expenditures on health in many less developed countries (World Bank 1997; Schopper and Walley 1992).

Overall, the World Bank study helps prioritize a country's rational use of drugs in the treatment of HIV/AIDS and provides a context within which to analyze the cost-effectiveness of antiretroviral or triple-drug therapy. When considering the costs of the drugs themselves, the costs and difficulty of monitoring complex treatment regimens, and the problems associated with patient compliance (all problems in the West, which are assumed be more severe in lower-income countries), the average costs per patient year in Thailand are a minimum of $8,000 and $12,000 in the United States and United Kingdom (World Bank 1997).

Even if drugs are made available, systems needs strengthening to support supply and rational use (UK NGOs 1997). Hence less developed countries are fertile grounds for comprehensive palliative care programs, where quality of life can be enhanced by the application of simple home remedies.

Moreover, research has shown that home-based care models can help reduce demand for hospital services and overall costs for care of HIV/AIDS patients. However, as mentioned above, the effectiveness of such home-based care is predicated on a well-functioning referral system and a supportive family structure. The financial efficiency of such programs was studied at Chikankata Hospital in Zambia, where the costs of all home visits during 1988 were shown to be less than the costs of hospital admissions that would have occurred in the absence of the home-care program. The study also showed a decrease in demand for inpatient services: an estimated 35 hospital admissions were prevented, and the average length of stay decreased from 32 to 16 days (Seeley et al. 1993; Schopper and Walley 1992).

The effect of outpatient and home-based care on hospitalization of HIV/AIDS patients was also examined in San Juan, Puerto Rico, before and after the

introduction of a comprehensive care system" (Schopper and Whalley 1992). The average hospital stay for AIDS patients decreased from 21.5 days to 11.3, with overall inpatient care accounting for 36 percent of care costs after the introduction of the comprehensive care system. However, it was not clear if the total costs of treatment for AIDS patient were decreased by this intervention (Schopper and Walley 1992).

PALLIATIVE CARE AS A FOUNDATION FOR HIV/AIDS PREVENTION

HIV/AIDS prevention and care often are seen to have separate objectives, areas of service, target populations, and resource allocations. While this distinction may help in the achievement of evaluation objectives, it becomes artificial in terms of program implementation and can actually become an obstacle (USAID 1995). In fact, much of the literature reviewed for this paper acknowledges that prevention and care are interdependent and that basic care and support serve as a foundation for HIV/AIDS prevention interventions:

> The dichotomy that has arisen between prevention and care during the pandemic is false — we need to acknowledge and advocate the close linkage between them and promote the notion that care and support for people with AIDS is a priority in its own right and presents valuable opportunities for providing information on how to prevent HIV transmission. (WHO 1995)

> In terms of both the individual and the community we cannot draw a line between preventive measures and care because they are closely linked and only credible and effective when applied together. Care for infected and diseased patients can be seen as a preventive measure, since personal involvement is the best way to promote a change in behavior. (Fleischer 1993)

As Joan MacNeil of USAID's AIDS Control and Prevention (AIDSCAP) Project put it:

> We know that it's almost impossible to separate the two at the practical level, especially in higher-prevalence countries. In fact, separating care and prevention may even undermine

> prevention efforts. If people living with HIV/AIDS feel abandoned by care services, they are less likely to acknowledge their status or to be motivated to protect others. (as quoted in Henry 1997)

Based on a review of over 20 of the projects it sponsored, the USAID–funded AIDS Control and Prevention (AIDSCAP) Project concluded that the provision of care for HIV–positive people has several benefits, which have been reported in other studies as well. (See Annex E for a grid of linkages between prevention and palliative care.)

- Care programs promote greater acceptance of HIV/AIDS as a community problem (AIDSCAP 1997).

> An evaluation of The AIDS Support Organization (TASO), a community-based support organization in Uganda, revealed that care, defined as medical treatment, counseling, and nursing care, helped people to plan for the future, practice safer sex, and seek early treatment for infections. Counseling also helped clients cope with HIV infection. Of the 730 TASO clients surveyed, 90% had revealed their serostatus, 79% felt their HIV status was accepted by their families, and 76% perceived acceptance in their communities. (MacNeil 1996)

Only when communities truly experience HIV/AIDS by acknowledging and participating in the care of those infected, will they be able to effectively think about prevention (USAID 1995). The Athlone Hopsital in the southern district of Botswana has developed a model of AIDS control by using “hands-on “ patient care in the wards as the starting point for prevention strategies into the community: “The project utilizes its units – ‘windows’ – of information, education, counseling, clinical care, pastoral care, home-based care, and training to involve the community in looking after itself” (Mapara 1998).

- Care programs reduce stigmatization and provide an entry point for discussions about behavior change (AIDSCAP 1997).
- Counseling, an important aspect of care, can play an important role in reducing risk behavior among people living with the disease (Henry 1997) — “The better care they receive, the less they may feel driven to risky behaviors” (USAID 1995).

- Peer educators and others are increasingly being called upon to provide care (AIDSCAP 1997).
- Integrating care and prevention can stretch resources further (USAID 1995). "The option of providing care and support services should not be weighed against funding and programming of prevention efforts, but should be seen as necessary to strengthening the prevention of the spread of HIV/AIDS" (MacInnis 1997).

Annex A: The World Health Organization's "Golden Rules" for Safe Food Preparation

1. **Choose foods processed for safety.**
   While many foods, such as fruits and vegetables, are best in their natural state, others simply are not safe unless they have been processed. For example, always buy pasteurized as opposed to raw milk. Certain foods eaten raw, such as lettuce, need thorough washing.

2. **Cook food thoroughly.**
   Many raw foods, most notably poultry, meats and unpasteurized milk, are very often contaminated with disease-causing pathogens. Thorough cooking will kill the pathogens, but remember that the temperature of all parts of the food much reach at least 70°C. If cooked chicken is still raw near the bone, cook it again until it's done — all the way through. Frozen meat, fish, and poultry must be thoroughly thawed before cooking.

3. **Eat cooked foods immediately.**
   When cooked foods cool to room temperature, microbes begin to proliferate. The longer they wait, the greater the risk. To be on the safe side, eat cooked food just as soon as they come off the heat.

4. **Store cooked foods carefully.**
   If you must prepare foods in advance or want to keep leftovers, be sure to store them under either hot (near or above 60°C) or cool (near or below 10°C) conditions. This rule is of vital importance if you plan to store foods for more than four or five hours. Foods for infants should not be stored at all.

   A common error, responsible for countless cases of foodborne disease, is putting too large a quantity of warm food in the refrigerator. In an overburdened refrigerator, cooked foods cannot cool to the core as quickly as they must. When the center of the food remains warm (above 10°C) for too long, microbes thrive, quickly proliferating to disease-producing levels.

5. **Reheat cooked foods thoroughly.**
   This is your best protection against microbes that may have developed during storage (proper storage slows down microbial growth but does not kill the organisms). Once again, thorough reheating means that all parts of the food must reach at least 70°C.

6. **Avoid contact between raw foods and cooked foods.**
   Safely cooked food can become contaminated through even the slightest contact with raw food. This cross-contamination can be direct, as when raw poultry meat comes into contact with cooked foods. It can also be more subtle. For example, don't prepare a raw chicken and then use the same unwashed cutting board and knife to carve the cooked bird. Doing so can reintroduce all the potential risks for microbial growth and subsequent illness prior to cooking.

7. **Wash hands repeatedly.**
   Wash hands thoroughly before you start preparing food and after every interruption--especially if you have been to the toilet. After preparing raw foods such as fish, meat, or poultry, wash again before you start handling other foods. And if you have an infection on your hand, be sure to bandage or cover it before preparing food. Remember too, that household pets often harbor dangerous pathogens that can pass from your hands into food.

8. **Keep all kitchen surfaces meticulously clean.**
   Since foods are so easily contaminated, any surface used for food preparation must be kept absolutely clean. Think of every food scrap, crumb or spot as a potential reservoir of germs. Cloths that come into contact with dishes and utensils should be changed every day and boiled before re-use. Separate cloths for cleaning the floors also require frequent washing.

9. **Protect foods from insects, rodents, and other animals.**

10. **Use clean water.**
    Clean water is just as important for food preparation as for drinking. If you have any doubts about the water supply, boil the water before adding it to food or making ice for drinks. Be especially careful with any water used to prepare an infant's meal.

Source: AIDS Action International. "Eat Healthily, Stay Healthy." AIDS Action, Online Issue 4, Health Action Information Network, 1998. Available from www.hain.org/aidsaction4/nutrition.html.

Annex B: Resources on Home Care for People with HIV/AIDS

Below is a list of publications and other information available on home care of people with HIV/AIDS

HOME CARE MANUALS

AIDS Home Care Handbook (Geneva: World Health Organization, 1993, UN Document No. WHO/GPA/HCS/93.2).

This manual provides information about counseling techniques, a story, and pictures that can be used by the community health worker to explain how HIV enters a family and the community and to prevent and manage the most common symptoms of HIV/AIDS. It includes advice about when to seek treatment outside of the home. It was developed collaboratively by WHO and The AIDS Support Organization (TASO) in Uganda and includes inputs from the Nsambya Hospital in Kampala and the Chikankata Mission Hospital in Mazabuka.

Only limited attention (a couple of paragraphs) is given in the manual on how to talk to the patient about preparing for death, and to talk with the family about what precautions they should take after their loved one has died.

The manual does little to address the psychosocial and spiritual aspects of the palliative care paradigm, but instead focuses on the medical aspects. These medical aspects are well handled and highly relevant for some African audiences, but the manual would need to be adapted for other use in other regions, as is being done by PAHO for the Latin, South American, and Caribbean regions.

Guidelines for the Domiciliary Care of People Living with HIV/AIDS (Washington, DC: Pan American Health Organization, forthcoming).[13]

PAHO is currently revising this adapted version of the WHO AIDS Home Care Manual for regional audiences. This manual includes chapters on identifying symptoms, when to go to hospital, universal precautions, how to change a bed, exercise, nutrition, emotional responses, etc. This regional model will be delivered via country workshops with the intention of adapting the regional model for country-specific use. (This manual was also adapted specifically for use in Guatemala.)

AIDS Care Outside the Hospital, by Dr. Ditch Townsend, 1998.

This is a community manual for Malaysia and moderate-resource Asian countries (40 pages; English). This takes a symptom-based rather than disease-based approach, covering fever, cough, diarrhea, vomiting, mouth sores, weight, rashes, pain, women, children, men, feelings, nervous system, food hygiene, and religion. The manual describes important problems, advises on basic self- treatment, and indicates when medical treatment is critical. (The manual was not available for review at time of this research.)

AIDS Care at Home: A Guide for Caregivers, Loved Ones, and People with AIDS, by J. Greif, and B. A. Golden (New York: John Wiley & Sons, Inc., 1994) .

AIDS Care: Diagnostic and Treatment Strategies for Health Workers, by E. Katabira, and R. Goodgame, Department of Medicine, Makerere University School of Medicine (Kampala: AIDS Control Programme, Ministy of Health, Republic of Uganda, 1989).

AIDS Action. (London: Appropriate Health Resources and Technologies Action Group Ltd., AHRTAG).

[13]The manual was not reviewed. The information is based upon a discussion with Dr. Rafael Muniz, Technical Director for AIDS, PAHO/Washington. The manual was developed in collaboration with CONASIDA, Mexico and INCAP, Guatemala.

These newsletters include pull-out sections on specific aspects of care.

Caring for People with AIDS at Home (Geneva: International Federation of Red Cross and Red Crescent Societies, 1993).

Living Positively - Nutrition Guide for People with HIV/AIDS (Mutare City, Zimbabwe: Mutare City Health Department). Not reviewed.

Living with AIDS in the Community (Geneva: World Health Organization, 1992, UN Document No. WHO/GPA/IDS/HCS/91.6).

Manipur Homecare Handbook, not reviewed

A Comprehensive Guide for the Care of Persons Living with HIV Disease: Module 4: Palliative Care (Toronto: Mt. Sinai Hospital and Casey House Hospice, 1995).

Training for Red Cross Volunteers to Teach Families to Care for People with Chronic Illness Including AIDS at Home: Homecare Curriculum, by M. Bizimungu, J. Karekezi, L. R. Bodil, H. Schietinger (Rwanda: Rwanda Red Cross, 1991).

Where Women Have No Doctor: A Health Guide for Women, by A. Burns, J. Lovich, and K. Shapiro. (Palo Alto, CA: The Hesperian Foundation, 1997).

Several chapters are directly relevant: Chapter 12: Sexual health; Chapter 16: STDs and other infections of the genitals; Chapter 17: AIDS; and Chapter 20: Sex workers.

TREATMENT GUIDELINES AND ALGORITHMS

Guidelines for the Clinical Management of HIV Infection in Children (Geneva; World Health Organization, November 1993, UN Document No. WHO/GPA/IDS/HCS/ 93.3).

Guidelines for the Clinical Management of HIV Infection in Adults (Geneva; World Health Organization, December 1991, UN Document No. WHO/GPA/IDS/HCS/ 93.3).

Guidelines on Sterilization and Disinfection Methods Effective Against Human Immunodeficiency Virus (HIV), AIDS Series No. 2, second edition (Geneva: World Health Organization, 1989).

Guidelines for Nursing Management of People Infected with Human Immunodeficiency Virus (HIV), AIDS Series No. 3 (Geneva: World Health Organization in collaboration with the International Council of Nurses, 1988).

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Annex D: Acronyms

Below is a list of the acronyms used in this report.

AIDSCAP	AIDS Control and Prevention Project
CDC	United States Centers for Disease Control
GPA	Global Programme on AIDS (WHO)
HAIN	Health Action Information Network (Quezon City, Philippines)
HCW	Health care workers
HTS	Health Technical Services Project
ICN	International Council of Nurses
IFRC	International Federation of Red Cross and Red Crescent Societies
LBM	Lean body mass
NGO	Nongovernmental organization
NIH	National Institutes of Health
NSAID	Non-steroidal anti-inflammatory agent
OI	Opportunistic infection
PAHO	Pan American Health Organization
PLWHA	Person/people living with HIV/AIDS
RDA	Recommended dietary allowances
SOBOMETRA	Society for Bolivian Traditional Medicine
TASO	The AIDS Support Organization (Uganda)
TB	Tuberculosis
UN	United Nations

UNAIDS	Joint United Nations Programme on HIV/AIDS
USAID	United States Agency for International Development
WHA	World Health Assembly (governing body of WHO)
WHO	World Health Organization
WHO/GPA	World Health Organization's Global Programme on AIDS (replaced on January 1, 1996, by UNAIDS)

Annex E: Prevention and Care Dynamic of Palliative Care Interventions

Figure 6. Prevention and Care Dynamic of Palliative Care Interventions				
Intervention	**Immediate Beneficiary**	**Primary Benefit**	**Mitigating Effect**	**Prevention Benefit**
Counseling (medical, psychosocial, emotional, spiritual, bereavement)	PLWHAS, families, caregivers	Coping with physical and psychosocial impacts of HIV disease, management of health, planning for dying	P Increases economic and social productivity of PLWHAs P Reduces firms' costs of labor absenteeism and diminished productivity P Reduces attrition of health care workers P Reduces social instability	Respond in a socially responsible manner, practice safe behaviors, reach out to support PLWHAs, provide HIV education in community
Treating the common ailments of HIV/AIDS and pain management	PLWHAS, families, caregivers	Alleviation of symptoms and increased independence, maintenance of well-being, enhanced quality of life	P Increases economic and social productivity of PLWHAs P Reduces firms' costs of labor absenteeism and diminished productivity	Provides opportunities for HCWs to counsel families in prevention (otherwise "missed opportunities); enables PLWHAs to remain well and provide education in community; provides models of hope

Figure 6. Prevention and Care Dynamic of Palliative Care Interventions				
Intervention	**Immediate Beneficiary**	**Primary Benefit**	**Mitigating Effect**	**Prevention Benefit**
Nutritional support	PLWHAS, families, caregivers	Increase stamina and longevity; enhanced quality of life	P Increases economic and social productivity of PLWHAs P Reduces firms' costs of labor absenteeism and diminished productivity	Prevents need for some marginalized groups to participate in unsafe behaviors because eliminates need to use sex for basic survival; provides concrete intervention of which the PLWHA has some control
Treatment of opportunistic infections	PLWHAS, families, caregivers	Enhances longevity and allows for PWLHA to remain productive; enhanced quality of life	P Increases economic and social productivity of PLWHAs P Reduces firms' costs of labor absenteeism and diminished productivity	Same as above; prevents spread of TB